

# **Change, Continuity and Diversity Among Caregivers**

Rhonda J. V. Montgomery, Ph.D.

Director, Gerontology Center  
University of Kansas

and

Karl D. Kosloski, Ph.D.

University of Nebraska at Omaha

## Table of Contents

<b>EXECUTIVE SUMMARY .....</b>	<b>3</b>
<b>INTRODUCTION.....</b>	<b>4</b>
<b>DIVERSITY OF CAREGIVING.....</b>	<b>4</b>
WHO ARE THE CAREGIVERS? .....	4
PATTERNS IN TASK PERFORMANCE.....	4
CARE SHARING .....	5
<b>THE MARKER FRAMEWORK AS A TOOL FOR DISCERNING.....</b>	<b>6</b>
CAREGIVING AS AN EMERGENT ROLE.....	6
CAREGIVING AS A DYNAMIC PROCESS.....	6
SEVEN MARKERS IN THE CAREGIVING TRAJECTORY .....	7
<b>DIVERSITY OF CAREGIVING IN THE CONTEXT OF THE MARKER FRAMEWORK</b>	<b>9</b>
DIFFERENCES IN THE CAREGIVING TRAJECTORIES OF SPOUSES AND CHILDREN .....	9
THE IMPACT OF CULTURE .....	11
<b>IMPLICATIONS FOR SERVICE USE.....</b>	<b>11</b>
CREATE MULTIPLE SERVICES TO MEET FULL RANGE OF NEEDS.....	11
CREATE SERVICES FOR THE MOST PREVALENT TYPES OF CAREGIVERS .....	11
EFFECTIVE TARGETING AND MARKETING OF SERVICES .....	12
CREATING LINKS BETWEEN SERVICES .....	13
<b>CONCLUSION.....</b>	<b>13</b>
<b>AUTHOR DESCRIPTION.....</b>	<b>14</b>
<b>REFERENCES .....</b>	<b>15</b>

## EXECUTIVE SUMMARY

Over the past few decades, research and program experience around family caregiving has shown that caregivers are very diverse in the manner in which they provide care and the consequences that they experience. The types and intensity of tasks that caregivers perform vary dramatically, depending upon the familial role of the caregiver. Evidence suggests that familial roles also influence how care is provided. The variability in caregiving behaviors indicates that the caregiving experience is significantly different for different types of caregivers. This paper highlights the diversity of caregiver experiences and provides a conceptual framework for program planners and administrators to better understand the implications of this diversity for the design and implementation of caregiver support services.

The “marker” framework discussed in this paper captures caregiving as a dynamic process and serves as a tool to gauge shifts in caregiving stages and receptivity to services and supports. The seven markers of this caregiving trajectory include: 1) performance of initial caregiving task; 2) self-definition as a caregiver; 3) provision of personal care; 4) seeking out or using assistive services; 5) consideration of institutionalization; 6) actual nursing home placement; and 7) termination of the caregiver role. The order and timing of markers 2 through 5 are considered defining characteristics of the caregiver experience and have direct relevance for implementing caregiver support programs. An important consideration is that the order and timing of these markers varies depending on the individual and type of caregiver (e.g., spouse versus adult children caregivers). In addition to the type of caregiver, an individual’s culture may play a significant role in the spacing of these markers.

Several implications for program design and delivery are presented. A key consideration for the Aging Network is the importance of creating multiple services that are flexible to meet the full range of needs of the community being served. In addition, states should be cognizant of limited resources and create services for the most prevalent types of caregivers in their community. Also, effective targeting and marketing of services should be used in order to reach caregivers at the “servable moment” point, not after it is too late. In offering respite, for example, only when caregivers reach the point at which they are providing extensive care and have identified themselves as caregivers will they reach the point of receptivity (the “servable moment”) to respite programs. Strategies to increase receptivity should be based on the understanding that different types of caregivers arrive at the “servable moment” for different reasons and that caregivers use services only when they perceive the benefits to outweigh the monetary, emotional, or physical costs of using the service. Lastly, programs should create institutional links between service providers in order to assist the caregiver in identifying services that best meet their needs at any point in the caregiving trajectory. This will enable a program to contend with the changing nature of the caregiving role. In the future, providers will be far more effective in their support efforts if they acknowledge and target both the diversity and the consistencies that social contexts create.

## **INTRODUCTION**

After more than two decades of research on family caregivers there is a general understanding that family members are the primary providers of long-term care. There is also consensus that these caregivers are very diverse in the manner in which they provide care and the consequences that they experience. Some family members thrive, some simply survive, and others suffer severe consequences. The purpose of this paper is to present a conceptual framework that recognizes this diversity in the caregiving experience and that can serve as a tool to guide the design and targeting of support services for family members who provide care for elderly persons.

## **DIVERSITY OF CAREGIVING**

### **Who are the Caregivers?**

The general consensus is that, most often, one family member serves as the primary source of care for an impaired elderly person, although others in the family and friend network may serve as “secondary caregivers.” The selection of the primary caregiver is associated with the family relationships, gender, and living arrangements of the family members (Cantor, 1979; Merrill, 1997). When available, a spouse provides the majority of care. In the absence of a spouse, a daughter is most likely to assume the role. In the absence of a daughter, a son will assume the role although there is considerable evidence that sons transfer many care tasks to their spouses. In the absence of offspring, other, more distant family members become responsible. The person designated to be the primary caregiver also tends to be the person with the fewest competing family or work obligations (Brody, 1990; Stern, 1996). The large majority (72 percent) of primary caregivers are women (Stone, Cafferata, & Sangl, 1987). Among all types of caregivers (primary and secondary) spouses comprise 36 percent; 29 percent are daughters; 8 percent are sons; 20 percent are other females and 7 percent are other male relatives. When the data are restricted to primary caregivers only, spouses account for almost half (48 percent) the caregivers, but women continue to comprise almost three quarters (74 percent) of caregivers. Very few sons or other male relatives serve as primary caregivers.

### **Patterns in Task Performance**

The types and intensity of tasks that caregivers perform vary dramatically, depending upon the familial role of the caregiver. Spouses report performing between 40 and 60 hours of caregiving tasks depending upon the study sample (Montgomery & Datwyler, 1990; Merrill, 1997). The majority of these hours are devoted to household chores, meal preparation and personal care, such as bathing, dressing and toileting. In contrast, adult children, on average, spend 15 to 30 hours per week performing care tasks. Children provide care for shorter periods of time and tend to concentrate their care activities on care management and assisting with transportation and shopping (Montgomery & Kosloski, 1994; Montgomery, Kosloski, & Datwyler, 1993).

In part, these differences between spouses and children in caregiving reflect differences in living arrangement. Virtually all spouses reside with their care recipient and consequently perform a wide range of care tasks as part of their everyday activities. Among adult children caregivers, a separate residence is more common for the care recipient. Yet, the living arrangement does not

fully account for all of the observed differences in care patterns because a large proportion of adult children who are caregivers do reside in the same household as the care recipient.

## Care Sharing

Spouses and adult children also differ in the way they share care responsibilities (Montgomery et al., 1993; Tennstedt, McKinlay, & Sullivan, 1989). When the primary caregiver is a spouse, adult children are most likely to serve as a secondary caregiver. When the primary caregiver is a child, secondary caregivers tend to be the spouse or sibling of the primary caregiver.

Despite their greater workload, spouses are the least likely among caregivers to seek and use formal support services (Stoller, 1992). This tendency is most pronounced for wives who tend to resist outside support to a greater degree than do husbands (Tennstedt et al., 1989). When the spouse is the primary caregiver, he or she performs 80 percent or more of the care tasks, which are usually concentrated on personal care and household chores (Stoller, 1992).

As secondary caregivers, children concentrate their efforts on tasks that are more consistent with their role as children, such as help with transportation, banking and paper work or sporadic household and yard maintenance activities. These tasks complement the care tasks of the spouse. For every type of care task, except help with legal and banking issues, daughters tend to provide more assistance than do sons. Daughters also concentrate their efforts on more routine care and distribute their hours more evenly across the various types of tasks (Tennstedt et al., 1989; Coward & Dwyer, 1990). Sons concentrate their efforts on tasks that are more circumscribed and sporadic, such as occasional shopping trips or annual yard and house maintenance activities (Matthews & Rosner, 1988). Sons provide less assistance to mothers than to fathers and they provide almost no help for mothers with personal care.

Adult children who are primary caregivers tend to share care tasks more equally with secondary caregivers than do spouses. When children assume both the primary and secondary caregiving roles, secondary caregivers tend to do similar tasks as primary caregivers and distribute their caregiving time among the various tasks in a similar manner. Consequently, the assistance provided by secondary caregivers in this family constellation tends to supplement the care provided by the primary caregivers (Montgomery et al., 1993; Tennstedt et al., 1989). Again, however, the sex of the caregivers involved tends to be associated with the patterns of care sharing. As primary caregivers, daughters provide a greater percentage of total care than do sons. Primary and secondary caregivers tend to share the care load almost equally when the primary caregiver is a son (Merrill, 1996). Like husbands, sons also tend to receive more assistance from formal service providers than do daughters (Merrill, 1997; Wright, 1983).

There is also some evidence that familial roles influence how care is to be provided (Goodman, Zarit, & Steiner, 1997). Corcoran and her colleagues (1992) report that men tend to use a managerial or linear approach to care wherein they identify physical tasks, and then perform these themselves, or delegate responsibility to other formal or informal providers. This task focus minimizes concern for psychosocial factors related to the care recipient and allows husbands to successfully accomplish measurable goals. Wives place greater importance on the emotional well being of their spouse and work to support their husband to maintain prior roles, activities, and positive self-esteem.

## THE MARKER FRAMEWORK AS A TOOL FOR DISCERNING

The differences in caregiving behaviors mean that the caregiving experience is significantly different for different types of caregivers. To better understand the implications of this diversity for the design and implementation of support services, it is useful to employ a conceptual framework that identifies important points in the caregiving trajectory that mark significant shifts in the caregiving experience.

The caregiving marker framework recognizes caregiving as a unique, dynamic process that nevertheless has uniform markers denoting shifts from one stage to another. The marker framework rests on two key premises. First, *there is no single, generic caregiver role*; rather caregiving is a role that emerges from prior role relationships. It is influenced by the unique values, beliefs, and circumstances of the role occupant. Consequently, as with other social roles, there are both consistencies in the process and unique adaptations. Second, *caregiving is a dynamic process that unfolds over time* and has been likened to a career of variable length (Montgomery & Hatch, 1987; Pearlin, 1992). As such, each caregiving history has (1) a beginning, (2) some definable temporal extension or duration, and (3) an end or resolution (e.g., recovery, death, or nursing home placement).

### Caregiving as an Emergent Role

To say that the caregiving role evolves out of another pre-existing familial role is to say that every caregiver has a prior relationship with the care recipient (i.e. husband, wife, daughter, or son). Consequently, each individual who assumes the caregiver role performs that role in a manner that is consistent with the expectations and obligations that accompany the initial relationship. The obligations and the expectations that a caregiver has as a spouse, a daughter, or a son, influence *how* and *to what extent* he or she assists the care recipient. These norms also influence the consequences that a caregiver experiences as a result of his or her caregiving behaviors.

Clearly within our society, the marital relationship is fundamentally different from the parent-child relationship in its history, expectations, and level of commitment, patterns of costs and rewards, and duration. Spousal caregiving emerges out of a reciprocal relationship where two persons have historically shared responsibility for each other's welfare and have voluntarily made a personal and legal commitment to care for one another. In contrast, the parent-child relationship has historically been asymmetrical in terms of responsibility. The parent has a moral and legal obligation to care for the child. Although, as the child becomes an adult, this relationship shifts from one of dependency for the child, parent-child relationships throughout the life cycle tend to remain asymmetrical, with care and assistance passing from parent to child until the parent becomes impaired (Pearlin, 1992). In combination with gender and cultural norms regarding the division of household labor and kin care, these differences in the initial dyadic relationship are reflected in consistent variations that have been observed in caregiving behaviors.

### Caregiving as a Dynamic Process

Although caregiving can be described in temporal units, the passage of time *per se* is unlikely to be an adequate descriptor of the caregiving situation. Tremendous variation exists in the trajectory of caregiving careers that a simple measure of time cannot reflect. The type and level of impairment that the care recipient exhibits, the relative stability of functioning level, and the

physical and social environment of the caregiving context can influence this variation in caregiving trajectories. As a result, knowing that a caregiving relationship has existed for twelve months does not provide a great deal of useful information about the specific needs of the caregiver, the caregiver's level of distress, nor the prospects for continued caregiving in the future. The marker framework identifies points in the caregiving trajectory that are not necessarily directly correlated with the passage of time, but they do serve as markers that are linked to significant changes in the caregiving experience.

## **Seven Markers in the Caregiving Trajectory**

The first marker in the caregiving trajectory is reached when a caregiver initially performs care tasks. The subsequent markers are: (2) self-definition as a caregiver, (3) provision of personal care, (4) seeking out or using assistive services, (5) consideration of institutionalization, (6) actual nursing home placement, and (7) termination of the caregiving role. Not every caregiver will reach each successive marker nor experience the event or status captured by each marker. The markers are presumed to be ordinal in their timing, but the order varies for different types of caregivers. Moreover the time between markers varies depending upon both structural and individual circumstances. The order of markers two through five and the differences in the time lag between these markers are viewed as important defining characteristics of the caregiver experience that have direct relevance for implementing caregiver support programs.

### ***Marker 1: Performing Caregiving Tasks***

The first marker of the caregiving career is the emergence of a dependency situation in which a family member or close acquaintance performs tasks designed to assist an older individual with routine activities previously performed without assistance. Initially these tasks include banking and money matters, shopping and transportation. With time, care tasks tend to include assistance with household chores, meal preparation and home maintenance, and ultimately, assistance with activities of daily living.

### ***Marker 2: Self-Definition as a Caregiver***

Marker #2 is reached when individuals come to view themselves as caregivers and incorporate this activity into their social or personal identity. Performing certain care tasks does not mean that individuals will define themselves as caregivers. Self-definition emerges when there is a shift in the nature of the initial relationship between the caregiver and the care recipient. For example, self-definition is likely to occur sooner in the caregiving process for adult children caregivers because assisting a parent represents a dramatic role shift. This is especially true if the care recipient changes residence to live with the care receiver.

In contrast, caregiving, at some level, is almost always part of the spousal role due to such factors as marital divisions of labor, power of status differentials, or individual differences in nurturance behavior. As a result, in the absence of a defining event (e.g., accident, heart attack, or stroke), the transition from spouse to caregiver may have an almost imperceptible onset and self-definition delayed.

***Marker 3: Performing Personal Care***

Marker #3 is reached when the caregiver begins providing personal care such as assistance with bathing, dressing, bladder and bowel evacuation, or other aspects of personal hygiene. For caregivers who are children, this marker often represents an important decision point regarding whether to continue in the caregiving role. Often personal care tasks involve physical contact between the caregiver and the care recipient, which is generally a taboo for parents and adult-children in our culture. Consequently, as the need for personal care increases for elders cared for by their children, the likelihood of terminating informal caregiving (e.g., institutionalization) increases substantially, especially for sons.

Whereas the need for personal care marks the end of informal caregiving for many children, it often signals an unambiguous start of caregiving for spouses. This delayed recognition of the caregiving role is especially likely when the care recipient has Alzheimer's disease and the provision of care to this point has involved tasks that could be viewed as spousal responsibilities. As a result, spouses are likely to reach markers #2 and #3 at approximately the same point in time and the order of the markers may be less consistent than for children. For spouses, the need for assistance with personal care is a graphic reminder that their relationship with the care recipient has changed in a significant way.

***Marker 4: Seeking Assistance and Formal Service Use***

Marker #4 is reached when the caregiver actively seeks out formal support services designed to assist informal caregivers. Such services include education programs, in-home respite, adult day care, counseling and support groups, chore or homemaker services, and home health care. A consistent observation of formal service providers and researchers has been that caregivers, especially spouses, seek formal assistance relatively late in the caregiving career (Montgomery, 1991). Clearly, the decision to seek services is dependent upon factors other than the disability level of the care recipient. Whether or not a caregiver will choose to use an assistive service is dependent on at least three judgments: (1) that one's condition or situation is deficient in some way; (2) that a particular service will enhance or offset that deficiency; and (3) that the benefits of using a particular service outweigh the costs (both psychological and monetary) (Kosloski & Montgomery, 1994). Services for which the costs outweigh the benefits to users are unlikely to be perceived as useful. For example, if the wife of an impaired older person adheres to the belief that she is responsible for her husband's care, she may well experience serious guilt or embarrassment if she seeks the help of an outsider. On the other hand, as the wife's health deteriorates or as the burden of care increases, due to the increasing demands of caregiving or perceived loss of a significant relationship, the benefits associated with outside assistance will increase.

To effectively target and serve caregivers, it is essential to understand the factors that prompt different types of caregivers to reach marker #4, the point at which they are receptive to support services. The frequent observation that many support services go unused likely reflects the fact that the services have been targeted to caregivers who have not yet reached marker #4, which can be considered the "servable" moment.



**Marker 5: Consideration of Nursing Home Placement**

The fifth marker is reached when the caregiver seriously considers placing the elder into a nursing home as an alternative to informal caregiving. The placement of this marker is not intended to suggest that caregivers never entertain thoughts of institutionalization until some point late in the caregiving career. Indeed, caregivers are first likely to consider institutionalization concurrently with self-identification as a caregiver. That is, self-identification results when the caregiver, having explicitly considered alternatives to caregiving (e.g., nursing home placement), rejects them in favor of the caregiving role. As changes in the caregiving situation occur, however, the caregiver may reconsider the earlier decision based on current circumstances. It is this reconsideration of placement in the context of terminating the caregiving role that characterizes marker #5.

Clearly, it is possible for caregivers to arrive at marker #5 without reaching marker #3 (performance of personal care) or marker #4 (use of services). This truncated trajectory, however, is most common for adult-children. In contrast, many caregivers, especially spouses caring for persons with Alzheimer's disease, arrive at marker #5 simultaneously or very shortly after arriving at marker #4. These caregivers likely account for the "too little, too late" phenomenon that has been observed in respite demonstrations (Montgomery & Borgatta, 1989; Gwyther, 1989). When caregivers fail to seek services prior to seriously considering nursing home placement, there is little opportunity for services to play a preventive role.

**Marker 6: Institutionalization**

The sixth marker is reached when nursing home placement occurs. As many dependent elders die without ever residing in a nursing home, not all caregivers reach this marker. Contrary to the preventive philosophy underlying support services for caregivers, past research has frequently reported a positive relationship between uses of support services (Hanley et al., 1990; Pruchno, Michaels, & Potashnik, 1990). This link between use of support services and nursing home placement may well be due to the fact that many caregivers, especially spouses do not reach marker #4, the point of willingness to seek services until very late in their caregiving trajectory.

**Marker 7: Termination of the Caregiving Role**

Marker #7, termination of the caregiving role, acknowledges that caregiving, like other social roles, can have an explicit end. There are three possible exit routes from the caregiving role: (1) death of the elder (or caregiver), (2) recovery of the elder, or (3) termination of the caregiving role (i.e., caregiver quits). The significance of this marker is that it acknowledges that care by informal caregivers continues to be provided after the elder has been institutionalized.

**DIVERSITY OF CAREGIVING IN THE CONTEXT OF THE MARKER FRAMEWORK****Differences in the Caregiving Trajectories of Spouses and Children**

The marker framework helps us to see that the greater propensity for spouses to provide more, and more intense, care than do adult-children is not solely a consequence of different levels of felt obligation. The careers of adult children and spouses are likely to differ both in terms of the factors that define the onset of the role and the factors that prompt family members to abdicate the role. Many of the tasks that children perform as caregivers (e.g. assistance with transportation,

banking and household chores), spouses perform as part of their marital role. Therefore, spouses tend not to recognize their caregiving role as unique from their spousal role—until they begin providing personal care. For many spouses, then, caregiving can have an almost imperceptible onset especially if the presenting problem is memory loss.

In contrast, for adult children the types of tasks that caregivers initially assume early along their trajectory, such as assistance with banking or shopping, represent a major role change for children. Therefore, children tend to identify themselves as caregivers at an earlier point in the caregiving process than do spouses. This earlier recognition of the caregiving role has three consequences. First, children more readily associate any strains that they experience in their lives as a result of added care tasks with the caregiving role. This attribution of strain to the caregiving role, prompts adult children to seek information and assistance earlier in the caregiving process. Finally, children tend to leave the caregiving role at earlier stages in the disease and dependency process (Montgomery & Kosloski, 1994). For children, the structural conditions that keep the person in the caregiving role are decidedly weaker. Since there are no legal obligations and limited familial expectations for adult children to provide care, those children for whom caregiving would be an extremely difficult proposition are unlikely to assume the caregiving role in the first place. And when caregiving interferes with other familial and work obligations, there are generally fewer normative and psychological sanctions (e.g. guilt) for abdicating the role (Merrill, 1997; Montgomery 1999).

Failing to recognize early care tasks as unique from the marital role, spouses are not likely to experience the caregiving role as burdensome or stressful until their afflicted mate is very dependent. Even then, their greater commitment appears to make them persist and endure in the caregiving role even if it involves extensive personal care (Doty, 1986). This greater endurance is demonstrated by the research findings that indicate that the level of functioning of the impaired elder and the level of objective burden of the spouse were not related to nursing home placement (Montgomery & Kosloski 1994). However, those spouses who reported a greater sense of obligation were less likely to place an elder.

In summary, the caregiving experience of adult-children tends to differ from that of spouses in several important ways. First, children have greater volition in their choice of the caregiving role and their choice of leaving the role than do spouses who express and demonstrate a greater obligation to this role (Montgomery, 1999). Second, the caregiving role of children tends to be more circumscribed and occurs in the earliest phases of the elder's impairment. Spouses do not define themselves as caregivers until the elder has reached a level of impairment at which most children abdicate the caregiving role (Montgomery & Borgatta, 1989). Consequently, spouses provide more care of all types and are far more likely to be providing personal care and extensive household care. Third, when spouses assume the caregiving role they tend to shoulder the majority of the care burden while children, especially sons, tend to share the workload more equally with their siblings or spouses. Finally, spouses who must contend with a significant change in the relationship that is most central to their lives find the role more emotionally stressful, while children report that the role impacts on their time, energy and other familial relationships (Stoller, 1992; Montgomery et al., 1993).

## **The Impact of Culture**

The marker framework also provides a useful tool for identifying and interpreting cultural differences in the caregiving experience (Lawton, Rajagopal, Brody, & Kleban, 1992; Merrill & Dill, 1990). Certainly there is cultural variation in the norms that are attached to familial roles. The “daughter” role in Latino families can be very different than the “daughter” role in Asian or Caucasian families. Moreover, in many minority cultures the “daughter” or “son” role may differ depending upon the birth order of the individual. Along with cultural differences in family structures, cultural differences in role norms, likely translate to variations in caregiving trajectories. Because minority women have a greater probability of being single, the prevalence of daughters as the primary caregiver is considerably greater among Black and Hispanic populations than among Caucasian populations. The limited number of studies of these cultural groups suggests that adult children account for almost 75 percent of the caregivers versus the 40 to 60 percent that have been found in studies of white populations (Chatters, Taylor, & Neighbors, 1989; Hinrichsen & Ramirez, 1992; Wallace, Snyder, Walker, & Ingman, 1992). Consequently, the daughters who care for minority elders tend to provide more household and personal care than do Caucasian daughters and they tend to express a need for and use more in-home services and adult day care when it is available (Hinrichsen & Ramirez, 1992; Wallace et al., 1992). At the same time, minority families tend to include a larger number of persons in the caregiving constellation (Chatters et al., 1989; Hinrichsen & Ramirez, 1992).

## **IMPLICATIONS FOR SERVICE USE**

### **Create Multiple Services to Meet Full Range of Needs**

The marker framework has several implications for the design and delivery of caregiver support services. First, and most important, it highlights the need for multiple support services to be available in multiple forms. Because caregivers arrive at their new role with very diverse histories, they also arrive with very different support needs. Consequently, some caregivers will simply need information; other caregivers will need emotional support and still others will need assistance with direct care tasks.

### **Create Services for the Most Prevalent Types of Caregivers**

In an ideal service system a unique package of services could be provided to meet the specific needs of every caregiving family. In the real world, support programs must operate within the limits of available resources. Therefore, it is important to create support services that are targeted to the groups of caregivers who are most prevalent and for whom the services will have the most effect. Within the context of the marker framework then it is important to assess the relative prevalence of caregivers who are spouses versus adult children in a catchments area because they are likely to have needs for different types of educational programs, support groups and respite.

For example, to be maximally useful an educational program must be designed to deliver the information that best matches a caregiver’s current needs. Since children reach marker #2 (self-identification as a caregiver) earlier in the caregiving process, they are likely to reach marker #4 (seeking help) prior to reaching marker #3 (the provision of personal care). Hence, their need for information is going to be quite different than that of spouse who seeks services much later in process. Children are more likely to seek information about the disease process, the availability of

community services, and legal and financial information. Spouses need help with coping skills and information about behavior management and about in-home support services. Educational needs are also going to be different for different cultural groups.

Educational programs are often linked with support groups for caregivers. In the past, caregivers have been shown to benefit from support groups through decreased stress and subjective burden, and increased active coping strategies and knowledge of community resources (Toseland, Labrecque, Goebel, & Whitney, 1992). Again, however, there is some evidence that spouses benefit from support groups in different ways than do adult children. In particular, support groups can help spouses cope with changes in their marital relationship, encourage them to seek outside help and to set aside time for themselves. Children benefit from support groups by extending their support network and gaining better knowledge of community services. There is also some evidence that support groups are more difficult for spouses to attend due to lack of transportation, lack of respite and greater dependence of the care receivers (Haley, 1989; Gonyea, 1989). Support groups have also been predominately attended by white and middle class caregivers (Haley, 1989).

There is also growing evidence that different forms of respite are more or less consistent with the needs of different types of caregivers. For example, a daughter who is employed outside of the home has need for an adult day care center that operates five days a week during working hours. In contrast, spouses who tend to care for more impaired elders often prefer in-home services that allow them short breaks away from home.

### **Effective Targeting and Marketing of Services**

The marker framework illustrates that a caregiver's willingness to use support services is associated with the point in the caregiver trajectory at which the caregiver is located. For example, despite considerable consensus about the value of respite services for alleviating caregiver stress and burden, a consistent lament of providers has been that these go unused, especially by spouses, who have been shown to seek formal assistance relatively late in the caregiving careers. This failure to use respite programs becomes understandable within the marker framework. Individuals who have not yet reached marker #2 do not yet define themselves as caregivers, and therefore, are not receptive to information directed toward "caregivers."

Similarly, in early phases of caregiving, respite is not really appropriate because caregivers generally are not performing intense care tasks and, in the case of children, are often not living with the care receiver. At the same time, spouses may not identify themselves as caregivers until the very late stages of their mate's dependency. Consequently spouses are likely to perceive information about respite programs directed toward "caregivers" as being largely irrelevant to them. Only when caregivers reach the point at which they are providing extensive care *and* have identified themselves as caregivers will they reach the point of full receptivity to respite programs. It is at this "servable moment" point, that respite programs can be expected to have their greatest impact (Kosloski & Montgomery, 1995).

On the other hand, if services are not made available at the "servable moment," caregivers may prematurely consider nursing home placement (e.g., marker #5) and move beyond the point at which they would be open to the use of support services. Often, when a spouse seeks assistance through formal providers he or she may already be considering relinquishing the caregiving role, due to the elder's consistent decline and increasing caregiver burden. This is the point at which

respite programs become “too little too late” and fail to serve a preventive function (Montgomery & Kosloski, 1994).

Simply put, caregivers will not use services for which they perceive no need or for which the monetary, emotional or physical costs of using the service outweigh the perceived benefits. Therefore, to effectively target support services, it is important to design them to meet the needs of different types of caregivers and to market them to the appropriate group at the point that they are receptive to using the service. With a better understanding of the factors that make caregivers receptive to service, it may also be possible to help caregivers reach the point of receptivity to services (marker #4) earlier in the caregiving experience. Strategies to increase receptivity, however, must be implemented with an understanding that different types of caregivers arrive at the “servable moment” for different reasons.

### **Creating Links between Services**

Finally, the marker framework emphasizes the importance of institutional links between support services that can be used to help caregivers find and use services that best meet their needs at any given point in time. It is unlikely that any one program will consistently meet a caregiver’s needs. Therefore it is important for programs to create institutional mechanisms for linking caregivers with new services when their needs change.

### **CONCLUSION**

Clearly the social context of caregiving dyads has significant impact on the caregiving experience and its consequences. The marker framework reminds us that attention must be given to ensuring the appropriate content of the support service or interventions, the appropriate “dosage” of the intervention, and flexibility of support programs to contend with the changing nature of the caregiving role. In the future, providers will be far more effective in their support efforts if they acknowledge and target both the diversity and the consistencies that social contexts create. Factors that must be considered for targeting include the family relationship and cultural background of the caregiver, and the marker at which a caregiver is located in the career process.

## AUTHOR DESCRIPTION

Rhonda Montgomery, Ph.D. is a Professor of Sociology and Director of the Gerontology Center at the University of Kansas. Dr. Montgomery has held research, administrative, and teaching positions at the University of Washington and Wayne State University. Over the past 20 years, Dr. Montgomery has conducted numerous regional and national studies focused on public policies and the role of family in providing long term care. She has served as a consultant and speaker for a wide range of professional and advocacy groups and is a past member of the National Board of Directors of the Alzheimer's Association and currently is a member of the Advisory Committee for Social and Behavioral Sciences for the Ronald and Nancy Regan Institute. Dr. Montgomery has published widely on issues related to families and aging, respite, and nursing home care.

Karl Kosloski, Ph.D. is a professor in the Department of Gerontology at the University of Nebraska at Omaha. Dr. Kosloski has performed a substantial amount of research and published a number of articles on caregiving including Kosloski, K., Montgomery, R., & Youngbauer, J. (2001). Utilization of respite services: A comparison of users, seekers, and non-seekers. *Journal of Applied Gerontology*, 20, 111-132; Kosloski, K., Young, R., & Montgomery, R. (1999). A new direction for intervention with depressed caregivers to Alzheimer's patients. *Family Relations*, 48, 373-379; and Kosloski, K., Montgomery, R., & Karner, T. (1999). Differences in the perceived need for assistive services by culturally diverse caregivers of dementia patients. *Journal of Applied Gerontology*, 18, 239-256.

## REFERENCES

- Brody, E. M. (1990). *Women in the middle: Their parent-child years*. New York: Springer Publishing Co.
- Cantor, M. (1979). Neighbors and friends: An overlooked resource in the informal support system. *Research on Aging, 1*, 434-63.
- Chatters, L. M., Taylor, R. J., & Neighbors, H. W. (1989). Size of informal helper network mobilized during a serious personal problem among Black Americans. *Journal of Marriage and the Family, 51*, 667-676.
- Corcoran, M. A. (1992). Gender differences in dementia management plans of spousal caregivers: Implications for Occupational Therapy. *The American Journal of Occupational Therapy, 46*(11), 1006-1012.
- Coward, R. T., & Dwyer, J. W. (1990). The association of gender, sibling network composition, and patterns of parent care by adult children. *Research on Aging, 12*, 158-181.
- Doty, P. (1986). Family care of the elderly: The role of public policy. *The Milbank Quarterly, 64*, 34-75.
- Goodman, C. R., Zarit, S. H., & Steiner, V. L. (1997). Personal orientation as a predictor of caregiver strain. *Aging and Mental Health, 1*(2), 149-157.
- Gottlieb, B. H., & Johnson, J. (2000). Respite programs for caregivers of persons with dementia: A review with practice implications. *Aging and Mental Health, 4*(2), 119-129.
- Gonyea, J. (1989). Alzheimer's disease support groups: An analysis of their structure, format, and perceived benefits. *Social Work in Health Care, 14*, 61-7.
- Gwyther, L. P. (1989). Overcoming barriers: Home care for dementia patients. *Caring, 8*, 12-16.
- Haley, W. E. (1989). Group intervention for dementia family caregivers: A longitudinal perspective. *The Gerontologist, 29*, 478-480.
- Hanley, R. J., Alecxih, L. M. B., Wiener, J. M., & Kennell, D. L. (1990). Predicting elderly nursing home admissions: Results from the 1982-2984 National Long-Term Care Survey. *Research on Aging, 12*, 199-228.

- Hinrichsen, G. A., & Ramirez, M. (1992). Black and white dementia caregivers: A comparison of their adaptation, adjustment, and service utilization. *The Gerontologist*, 32, 375-390.
- Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist*, 33, 240-248.
- Kosloski, K., & Montgomery, R. J. V. (1994). Service use by family caregivers of Alzheimer's patients. *Seminars in Speech and Language*, 15, 226-235.
- Kosloski, K. D., & Montgomery, R. J. V. (1995). The impact of respite use on nursing home placement. *The Gerontologist*, 35, 67-74.
- Lawton, M., Brody, E., & Saperstein, A. (1989). A controlled study of respite service for caregivers of Alzheimer's patients. *The Gerontologist*, 29, 8-16.
- Lawton, M. P., Rajagopal, D., Brody, E., & Kleban, M. H. (1992). The dynamics of caregiving for a demented elder among black and white families. *Journal of Social Sciences*, 47B, S156-S164.
- Matthews, S. H. (1995). Gender and the division of filial responsibility between lone sisters and their brothers. *Journal of Gerontology: Social Sciences*, 50B, S312-S320.
- Matthews, S. H., & Rosner, T. T. (1988). Shared filial responsibility: The family as the primary caregiver. *Journal of Marriage and the Family*, 50, 185-195.
- Merrill, D. (1996). Conflict and cooperation among adult siblings during the transition to role of filial caregiver. *Journal of Social & Personal Relationships*, 13, 399-413.
- Merrill, D. (1997). *Caring for elderly parents: Juggling work, family, and caregiving in middle and working class families*. Westport, CT: Auburn House.
- Merrill, D., & Dill, A. (1990). Ethnic differences in older mother-daughter co-residence. *Ethnic Groups*, 8, 201-213.
- Mittelman, M. S., Ferris, S. H., Steinberg, G., Shulman, E., Mackell, J. A., Ambinder, A., & Cohen, J. (1993). An intervention that delays institutionalization of Alzheimer's Disease patients: Treatment of spouse-caregivers. *The Gerontologist*, 33, 730-740.
- Montgomery, R. J. V. (1991). Examining respite: Its promise and limits. In M. Ory & A. Dunker (Eds.), *In home health and supportive services for older people* (pp. 75-96). Newbury Park, CA: Sage Publications, Inc.



- Montgomery, R. J. V. (1999). The family role in the context of long-term care. *Journal of Aging and Health, 11*(3), 383-416.
- Montgomery, R. J. V., & Borgatta, E. F. (1989). The effects of alternative support strategies on family caregiving. *The Gerontologist, 29*, 457-464.
- Montgomery, R. J. V., & Datwyler, M. M. (1990). Women and men in the caregiving role. *Generations, (Summer)*, 34-38.
- Montgomery, R. J. V., & Hatch, L. (1987). The feasibility of volunteers and families forming a partnership for caregiving. In T. Brubaker (Ed.), *Family and long-term care*, (pp. 143-161). Beverly Hills, CA: Sage Publications.
- Montgomery, R. J. V., & Kosloski, K. (1994). A longitudinal analysis of nursing home placement for dependent elders cared for by spouses vs. adult children. *Journal of Gerontology: Social Sciences, 49*, S62-S74.
- Montgomery, R. J. V., & Kosloski, K. D. (1995). Respite revisited: Re-assessing the impact. In P. Katz, R. Kane, & M. Mezey (Eds.), *Quality care in geriatric settings: Focus on ethnic issues* (pp.47-67), New York: Springer Publishing Company.
- Montgomery, R. J. V., Kosloski, K. D., & Datwyler, M. M. (1993). *Factors defining caregivers: Final Report to the National Institute on Aging*. (Grant No. R01-AG05702), Gerontology Center, University of Kansas, Lawrence, KS.
- Pearlin, L. I. (1992). The careers of caregivers. *The Gerontologist, 32*, 647.
- Pruchno, R., Michaels, J., & Potashnik, S. (1990). Predictors of institutionalization among Alzheimer disease victims with caregiving spouses. *Journal of Gerontology: Social Sciences, 45B*, S259-S266.
- Stern, S. (1996). Measuring child work and residence adjustments to parents' long-term care needs. *The Gerontologist, 36*, 76-87.
- Stoller, E. P. (1992). Gender differences in the experiences of caregiving spouses. In J. W. Dwyer & R. T. Coward (Eds.), *Gender and family care of the elderly*, (pp. 49-64). Newbury Park, CA: Sage Publications.
- Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist, 27*, 616-626.
- Tennstedt, S., McKinlay, J., & Sullivan, L. M. (1989). Informal care for frail older persons: The role of secondary caregivers. *The Gerontologist, 29*, 677-683.
- Toseland, R. W., Labrecque, M. S., Goebel, S. T., & Whitney, M. H. (1992). An evaluation of a group program for spouses of frail elderly veterans. *The Gerontologist, 32*, 382-390.

- Toseland, R. W., & Rossiter, C. M. (1989). Group interventions to support family caregivers: A review and analysis. *The Gerontologist*, 29, 428-448.
- Wallace, S. P., Campbell, K., & Lew-Ting, C. Y. (1994). Structural barriers to the use of formal in-home services by elderly Latinos. *Journal of Gerontology: Social Sciences*, 49B, S253-263.
- Wallace, S. P., Snyder, J. L., Walker, G. K., & Ingman, S. R. (1992). Racial differences among users of long-term care: The case of adult day care. *Research on Aging*, 14, 471-495.
- Wright, F. (1983). Single careers: Employment, housework, and caring. In J. Finch and D. Groves (Eds.), *A labour of love: Women, working, and caring* (pp. 89-105). London: Routledge and Kegan Paul.
- Zarit, S. (1990). Interventions with frail elders and their families: Are they effective and why? In M. Stephens, J. Crowther, S. Hobfoll, & D. Tennenbaum (Eds.), *Stress and coping in later-life families*. New York: Hemisphere Publishing.